Fulfilling reproductive rights for women affected by HIV
A tool for monitoring achievement of Millennium Development Goals

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PREFACE

On 8 March 2004, over 25 national and international organizations presented a statement to the secretariat of the UN Commission on the Status of Women that highlighted neglected areas in HIV-positive women's reproductive health.[1] Representatives of four organizations – Ipas, the International Community of Women Living with HIV/AIDS (ICW), the Pacific Institute for Women's Health and the Center for Health and Gender Equity (CHANGE) – used that statement to develop this practical tool to help address those areas of reproductive health: involvement of HIV-positive women in policymaking and program implementation, fertility control that meets HIV-positive women's needs, and research on antiretroviral therapy in relation to fertility.

Why develop this tool?

Many NGOs and community-based organizations (CBOs) have no formal or extensive research capacity. They are unable to conduct large-scale baseline and follow-up surveys and therefore are not in a position to measure percentage increases and decreases in various indicators.

Nevertheless, many organizations can collect information useful for assessing whether progress has been made in fulfilling complete reproductive rights for women living with HIV. The set of simple benchmarks and accompanying questions proposed in this document can serve as a tool for such an exercise. Data to answer the questions can be gathered through both qualitative and quantitative means; in some cases, answers can be found simply by reviewing available documents and interviewing staff of organizations involved in HIV/AIDS work.

By linking the questions to the Millennium Development Goals (MDGs), we hope that somewhat comparable data across countries and regions can be collected once yearly for presentation at national and international venues where HIV/AIDS policies and programs are formulated and reviewed. The benchmarks and questions can be refined as time goes by.

This document is organized as follows:

- Section 1 introduces the relevant MDGs and neglected areas of reproductive health.
- Section 2 contains brief background information on the issues.
- Section 3 provides the data collection questions linked to MDGs 5 and 6.
- Section 4 gives some ideas on how the collected data can be used.
- Section 5 lists the organizations that support use of this tool.

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1. INTRODUCTION

Two of the UN-endorsed Millennium Development Goals (MDGs) are directly related to the reproductive health of women living with HIV.[2] MDG 5 aims to improve maternal health by reducing the maternal mortality ratio by 75%, while MDG 6 aims to halt and begin to reverse the spread of HIV/AIDS. In this context, the UNAIDS Global Coalition on Women and AIDS has recognized that women's and girls' vulnerability to HIV infection and the impact of AIDS are linked to gender inequalities and societal norms that need to be challenged.[3]

To ensure that all reproductive rights for HIV-positive women are fulfilled, policies and programs especially need to challenge inequalities and gender-biased norms regarding relatively neglected areas of women's health. These neglected areas include:

- Ensuring that HIV-positive women and their networks are involved both in policy-making and implementation of reproductive health care
- Expanding access to, and ensuring that no woman is coerced into, voluntary HIV counseling and testing, including women receiving postpartum care, emergency contraception and rape crisis services, and abortion-related care
- Expanding access to post-exposure prophylaxis following unprotected sex, including sexual assault, as a measure to reduce HIV transmission
- Expanding access to modern contraceptive methods, including emergency contraception, and ensuring that information provision on contraceptive methods is tailored to the needs of women living with HIV
- Ensuring that HIV-positive women have the right to have children when they want to, and should be supported to do so, without judgment and with access to antenatal, perinatal and postnatal care
- Ensuring that sterilization of HIV-positive women only occurs when each woman concerned gives her full, informed and unpressured consent
- Ensuring that reproductive health programs for HIV-positive women include high-quality postabortion care and measures to enable women to access safe, legal abortions
- Raising the visibility of, and access to, assisted reproduction techniques and possibilities of fostering and adopting children as additional parenting options for people living with HIV.

- Increasing research on the effects of antiretroviral drugs on women's bodies, especially in relation to fertility.

2. BACKGROUND

Voluntary HIV counseling and testing

Voluntary HIV counseling and testing (VCT) is being widely promoted as a component of antenatal care. Increasingly, antenatal VCT is becoming routine and women are unaware of, or denied, the chance to opt out of testing at this time. Moreover, because large numbers of women do not receive antenatal VCT, some organizations are recommending that VCT not only be offered during pregnancy but also during labor and delivery.[4-7] Yet little research has been done on how pre- and post-test counseling can be done during the intra-partum period. There is also little research on the psycho-social effects on women of receiving an HIV-positive diagnosis at *any* stage during or after her pregnancy, which is often a time of great emotional, as well as physical, experiences.

Furthermore, in some countries, women who are identified as being HIV-positive through antenatal VCT have been pressured to have abortions or to be sterilized following childbirth.[8-10] In other cases, women have been turned away from hospitals and clinics for care at delivery because of health-care professionals' fears of occupational exposure to the virus. A failure to offer adequate pre- and post-test counseling, pressure or coercion to undergo sterilization or terminate pregnancies, and denial of care are all clear violations of HIV-positive women's reproductive rights.[11] **Therefore,**

VCT should be truly voluntary and available to women *and men* at *all* entry points into the health-care system, rather than just for women when pregnant.

If the purpose of VCT is not only to prevent perinatal transmission but also to enable women to take care of their own health, all pregnant women should be offered VCT, including those who seek induced abortions and women receiving postabortion care.

Until VCT sites are widely accessible, women who receive gynecological care, maternal-child health services, family planning, and rape crisis services should also be offered VCT.

Sexual assault

Many women and girls around the world are vulnerable to HIV/STIs because they have less decision-making power about whether and when to have sex due to gender-based inequalities in relationships. High numbers of women and girls suffer sexual assault, both within and outside marriage and steady relationships. These rapes and cases of

incest put them at risk of both HIV/STI infection and re-infection and unwanted pregnancies. Moreover, where laws criminalize transmission of HIV, HIV-positive women who are forced into sexual intercourse may also face grave consequences.

> "Some women decide not to have sex but face abuse instead….One young woman living with HIV I know did not want to have sex and was raped by a man. He did not know her HIV status. After discovering her status, her family and that of the rapist blamed her for transmitting HIV to the rapist." - personal testimony, HIV-positive young woman, South Africa[12]

Access to **post-exposure prophylaxis** following unprotected sex is non-existent for the great majority of women worldwide. **Greater efforts are needed to expand accessibility to this HIV prevention measure.**

Contraception

Many women and girls around the world do not have **access to modern contraceptive methods.** WHO has pointed out that access to contraceptive methods for HIV-positive women in the postpartum period is also **still limited.**[13] On the other hand, in some places one of the criteria that women must fulfill to receive antiretroviral therapy, outside the setting of programs to prevent perinatal transmission, is that they use injectable contraceptives; this is a violation of their right to choose which method they want. When they do have access, they still may **not** receive sufficient information **tailored to their needs.** For example, as antiretroviral therapy becomes more widely available, women will need to know about possible interactions between hormonal contraceptives and antiretroviral medications.[14]

When condoms are used without another contraceptive method, women's chances of having an accidental pregnancy within a 12-month period with typical use are about 14% for male condoms and about 21% with female condoms.[15] Unwanted pregnancies also result from failures with other contraceptive methods and sexual assault. Although access to emergency contraception is increasing, many women still do not know about it or where to obtain it.

Policies and regulations are needed to expand access to emergency contraception, including availability over-the-counter and as a prophylactic measure (i.e., women receive supplies from their physician in advance of need).

Termination of pregnancy

The 20 million women who terminate pregnancies unsafely each year include HIV-positive women in countries with restrictive abortion laws. In reaffirming the ICPD Programme of Action at its five-year review in 1999, the UN General Assembly stated

that “All Governments and relevant intergovernmental and non-governmental organizations are urged to strengthen their commitment to women’s health, to deal with the health impact of unsafe abortion as a major public-health concern” and ”In circumstances where abortion is not against the law, such abortion should be safe.” They further said that: “In recognizing and implementing the above, and in circumstances where abortion is not against the law, health systems should train and equip health-service providers and should take other measures to ensure that such abortion is safe and accessible.”[16]

The Treaty Monitoring Committee for the Convention on the Rights of the Child emphasized that “States parties should take measures to reduce maternal morbidity and mortality in adolescent girls, particularly caused by early pregnancy and unsafe abortion practices” and urged “States parties (a) to develop and implement programmes that provide access to sexual and reproductive health services, including family planning, contraception and safe abortion services where abortion is not against the law.”[17] **Policy-makers and program implementers working in the field of HIV/AIDS need to follow up these recommendations and ensure that reproductive health care for women living with HIV is governed solely by each woman’s own fully informed and non-coerced choice. Services should include the following high-quality options: antenatal, perinatal and postnatal care, when requested, both for woman and baby; postabortion care and measures to ensure women’s access to safe, legal abortions when requested; and safe sterilization, again only when requested.**

Assisted reproduction

Insufficient attention is being given to additional parenting options for women and men living with HIV. **Assisted reproduction techniques** can make it possible for couples to have pregnancies in which the HIV-negative partner is protected against infection. The techniques used include sperm washing and artificial insemination, intrauterine insemination, and in vitro fertilization with intracytoplasmic sperm injection whereby an oocyte is exposed to only one selected sperm to minimize contamination with cellular material. Studies in France, Italy, the United Kingdom and the USA have shown these techniques to be relatively safe and successful, although higher rates of pregnancy have been achieved with procedures carried out on behalf of HIV-positive men than for HIV-positive women.[18-21]

Foster care and adoption

As more people gain access to antiretroviral therapy and their HIV infection becomes a more chronic, rather than fatal, condition, they may wish to consider **fostering or adopting children**. Yet policies and laws may pose obstacles to them exercising these options. **Policy-makers and advocates need to make these parenting options more visible and accessible to people living with HIV. More research is also needed on maternal death rates and orphan survival vis-à-vis HIV/AIDS.**

Antiretroviral therapy and fertility
Many treatment access programs fail to take the specific needs of women into account. Pregnancy is addressed primarily through programs to prevent perinatal transmission. **Much more research is needed, including studies on the impact and side effects of antiretroviral drugs on teenage and adult women's bodies, particularly in relation to fertility, pregnancy and childbirth.**

3. BENCHMARKS AND QUESTIONS FOR DATA COLLECTION

The broadly-formulated Millennium Development Goals will be difficult for many countries to achieve by 2015; however, intermediate benchmark indicators can help us mark progress towards achieving the MDGs. The following benchmarks and questions have been formulated to help establish a baseline regarding the neglected areas of HIV-positive women's reproductive health described in this paper. The questions can be applied at a local (e.g., a city, district or province/state) or national level. By posing the same questions again in 6 months' to a year's time, increases or decreases in desired results can be assessed.

Benchmarks & questions for MDG 5: Improving maternal health

1. All funders allow health programs to address *all* areas of HIV-positive women's reproductive health.
   How many bilateral agreements or donor grants to HIV, maternal health, and sexual and reproductive programs contain provisions restricting work on specific areas of reproductive health for women affected by, and living with, HIV? If so, what restrictions are named?

2. All funders require programs serving HIV-positive women to include them in policy and program design.
   How many bilateral agreements or donor grants for perinatal transmission prevention and health-care programs for women living with HIV require that HIV-positive women's associations are involved in policy and program formulation, implementation and monitoring/evaluation?

3. All programs serving HIV-positive women include counseling, support and drug treatment components.
   How many grants include funding for counseling, self-help groups, drugs for opportunistic infections and antiretroviral drugs?

4. All agencies serving HIV-positive women publicly endorse documents listing their reproductive rights.

How many NGOs, prevention of perinatal transmission programs and health facilities (in a country, district, city) have adopted the *Barcelona Bill of Rights* or the guidelines on HIV/AIDS and human rights issued by UNAIDS and the Office of the UN High Commissioner on Human Rights as a guide for action and display it in their facilities?

5. All women have access to family planning information that addresses contraception in relation to HIV/AIDS.
   How many organizations have created materials on contraceptives that also address issues of concern to people living with HIV (e.g., dual protection, use of emergency contraception, breakthrough bleeding or spotting, possible interactions between hormonal contraceptives and drugs used to treat HIV and opportunistic infections)? What kinds of materials are available?

6. All organizations serving HIV-positive women address all available legal options for preventing and avoiding unwanted pregnancy.
   How many organizations have created materials specifically for women living with HIV that discuss options for avoiding unwanted pregnancies, such as female and male condoms, microbicide research, emergency contraception and safe legal abortion? What kinds of materials are available?

7. All women, including HIV-positive adolescents and adults, have easy and affordable access to emergency contraception.
   How many health or other facilities offer emergency contraception without a prescription or as a prophylactic measure and how many women known to be living with HIV have been able to access such contraceptive services (within a specified time period)?

8. VCT is available at women-centered health-care services besides antenatal and delivery care.
   How many health facilities offering postpartum care, rape crisis services, postabortion care and induced abortions offer voluntary HIV counseling and testing or referrals for VCT?
   How many referrals for VCT were made by health facilities offering postpartum care, rape crisis services, postabortion care and induced abortion within (specified time period)?
   How many maternal health services, other than antenatal care, have established and formalized VCT or a referral system for VCT?

9. Gender-sensitive research is being conducted on how antiretroviral drugs affect reproductive functions.

How many studies are being done locally to assess the impact of antiretroviral therapy on women's bodies, particularly in relation to fertility?

10. Women's choices on how to regulate their fertility do not prevent them from accessing antiretroviral therapy.
    Do antiretroviral treatment programs require women to use certain fertility regulation methods as a criterion for enrolment?

11. Health-care based stigma and discrimination in relation to HIV/AIDS has been successfully eradicated.
    How many (documented) instances of stigmatization and discrimination against women living with HIV/AIDS by personnel in the health-care sector have been reported to legal authorities or AIDS-related organizations?
    In which areas of health care have stigma and discrimination been documented (e.g., family planning, gynecological care, antenatal care, childbirth, postpartum care, abortion-related care)?

Benchmarks & questions for MDG 6: Combating HIV/AIDS

1. Civil society organizations, including associations of HIV-positive women, are enabled to participate in government-sponsored HIV/AIDS programs.
   Do bilateral agreements supporting HIV/AIDS programs contain provisions requiring partnerships with civil society? If so, what are the specific requirements?

2. HIV-positive women's needs are taken into account in bilateral agreements.
   Do bilateral agreements supporting HIV/AIDS programs include measures that will specifically benefit women living with HIV? If so, what measures are included?

3. Collaboration between civil society and governmental and intergovernmental agency-sponsored has resulted in improved programs for HIV-positive women.
   Has collaboration between NGOs, including associations of HIV-positive women, and governmental, UN agency or other mainstream service providers taken place? If so, what concrete activities have been carried out to improve women's lives?

4. Measures have been taken to minimize chances of HIV infection in women who have been subjected to coerced or forced sex, both within and outside marriage.
   How many health facilities offer post-exposure prophylaxis (PEP) for unprotected sex and how many women have benefited from PEP (within a specified time period)?

5. HIV-positive women are informed about all their legal options for controlling their fertility.

How many NGOs and AIDS-related organizations have provided information, counseling and support to HIV-positive women about their right to fulfill their own reproductive intentions as they desire?

6. HIV-positive women and men are informed about all their legal options for parenting children.
   How many NGOs and AIDS-related organizations have included the options of assisted reproduction and fostering/adopting by HIV-positive people in their advocacy materials and actions?

4. HOW THE BENCHMARKS AND QUESTION ANSWERS CAN BE USED

Global and regional levels

This document can be presented to key actors for endorsement at international meetings, such as AIDS conferences, and National AIDS Program reviews. It can also be used for advocacy and monitoring purposes in conjunction with regional agencies that are considering the MDGs, such as the New Partnership for Africa's Development (NEPAD).

At the international level, organizations can endorse use of this monitoring tool to encourage support for its use. Sign-on will be a continuous process through Ipas (e-mail: debruynm@ipas.org). Each month, organizations will be able to download a version of the document with the newest signatures so that they have an updated resource for advocacy.

The NGOs that developed this tool will assume responsibility for collating data collected at the national (and/or local levels) by participating organizations so that a yearly overview of progress around the world is made available to intergovernmental and governmental actors. They will do this by contacting organizations that endorsed the tool at the end of 2004 and 2005.

The national level

- Participating NGOs can invite key actors within a specified geographical area to a meeting at which this document and the *Barcelona Bill of Rights* are introduced, e.g., as part of feedback sessions that report on the international AIDS conference.
- At this meeting, participating organizations can decide which benchmark indicators will be useful for monitoring work in their geographical area. Individual participants can be asked to collect baseline data using specific questions; the answer data can be delivered to one central body (e.g., an AIDS network office).

- Plans can be made to organize a follow-up meeting within 6 months or one year where follow-up data are reviewed to assess the extent to which progress has been achieved.
- An overview of the data collected at one year's time can be sent to the international NGOs mentioned above for the overall worldwide progress overview.

5. ORGANIZATIONS & INDIVIDUALS ENDORSING THIS MONITORING TOOL

- Action Canada for Population and Development (ACPD)
- Australian Reproductive Health Alliance
- Center for Health and Gender Equity (CHANGE)
- CHOICE, for youth and sexuality, The Netherlands
- Equilibres & Populations, France
- Federation for Women and Family Planning, Poland
- FEIM, Argentina
- Flora Tristán, Peru
- Gender AIDS Forum, South Africa
- Jashodhara Dasgupta, KRITI Resource Centre, India
- International Women and AIDS Caucus, International AIDS Society
- International Community of Women Living with HIV/AIDS (ICW)
- Ipas
- Pacific Institute for Women's Health
- Punto de Encuentro de la Comunidad, A.C., Mexico
- Susan Paxton, consultant, Asia-Pacific Network of People Living with HIV/AIDS (APN+)
- Women Fighting against AIDS in Kenya (WOFAK)
- Women for Women's Human Rights - NEW WAYS, Turkey
- World Population Foundation, The Netherlands

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